

PSJ4 SOL Opp Exh 9

MANY OF YOU HAVE WRITTEN
AND CALLED PURDUE PHARMA
ASKING FOR A WAY TO HELP KEEP
APPROPRIATE PAIN MEDICATION
AVAILABLE.

THIS TOOLKIT IS PURDUE'S
RESPONSE TO THOSE REQUESTS.

PARTNERS AGAINST PAIN

Pain Control Advocacy Toolkit



Simple ways to:

- prevent “suffering in silence”
- gain positive action and support for pain sufferers

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Dear Colleagues in Healthcare

During the past ten years, pain management issues have become more visible to both patients and healthcare providers. New national pain management standards of care and treatment protocols have been implemented widely, and the Joint Commission on Accreditation of Hospital Organizations has imposed requirements for adequate pain management. Position statements on the use of opioid analgesics for the treatment of chronic pain have been issued by the Federation of State Medical Boards, the American Pain Society and the American Academy of Pain Medicine. And perhaps most important, innovative medications and delivery systems are now available for the effective treatment of chronic pain.

Yes, we have made progress. But the advances we have made in patient care are in danger of being slowed or reversed.

Purdue Pharma, L.P. has received a steady increase in requests from patient groups, healthcare professionals and civic organizations for assistance in getting their needs heard and appropriately acknowledged. There is growing concern that once again patients will have to “suffer in silence” with sub-optimal treatment.

The time has come to ensure that appropriate pain management is in the forefront of the minds of public officials and medical gatekeepers who can lend us the support we need. We must tell them about the treatment gaps and impediments to optimal care we’ve been enduring by sharing our suffering “out loud”. “Out loud” so it can no longer be ignored, and “out loud” so that

appropriate care and effective medications will not be withheld from those we love and care for.

It is the goal of this handbook to give patients, their healthcare providers, their caregivers and other advocates simple tools to express a strong and organized voice in the media and powerful governmental circles – tools that will help ensure that the case for pain management will be heard and access to appropriate treatment will be rapidly improved.

Some of the tools catalogued here will be more suitable to you (or your group) than others. Feel free to choose the tools that you are most comfortable working with in making your story heard. Your voice and the voices of your group really count in dealing with these issues. Only a *combined chorus* of all of our voices in the press, in legislatures and among medical and public officials will be sufficient to fully empower the drive for swift, appropriate pain control.

You have my personal commitment, and the commitment of the other dedicated professionals of Purdue Pharma, to do whatever it takes to assist you in accomplishing this task.

A handwritten signature in black ink, reading "Pamela Bennett R.N.B.S.N." with a stylized flourish at the end.

Pamela Bennett, R.N., B.S.N.
Director, Advocacy
Purdue Pharma L.P.

How You Can Help Prevent “Suffering in Silence”

Advocacy – calling attention to the needs of sufferers of chronic diseases – has become a very effective communications strategy. Because there are so many healthcare issues today, the message of chronic and cancer pain sufferers must be heard above the daily level of background noise about medical politics and economics that officials are exposed to everyday—just as we are--- on TV, radio and in the newspapers and magazines we all read.

To truly “be heard,” you need to address those who can act on your behalf with a message that expresses your needs in a simple fashion and is repeated by a combined chorus of all our voices.

One reason cancer patients finally have greater access to medications in late stages of research is that cancer groups learned how to deliver their messages repeatedly and effectively. Partners in that success story are the men and women with AIDS who formed the organization “Act-Up”. Those AIDS treatment activists literally tutored the cancer advocates on how to be heard and gain access to medications at earlier stages.

Similar patient and professional advocacy action is what brought vaginal anti-fungal products to over-the-counter status, so patients could buy them at lower prices without the cost of a medical visit for what is a routine feminine condition. Later patients and professionals used advocacy tools to

de-stigmatize depression—forever establishing the fact that depression is not a “weakness,” but instead, an easily treatable medical condition.

When you utilize the simple communications tools in this handbook, you’ll be harnessing the same powerful communications process that worked so well in the examples we’ve just cited. You have important pain management information and experience to communicate, so use these tools to let those who have suffered in silence be heard---NOW IS THE TIME!

Why Immediate and Sustained Civic Action is Needed

All innovative opioid analgesics are put at risk when criminals steal and sell these vitally needed treatments and drug abusers buy and misuse them. It is not surprising that this criminal activity sometimes places a perverted twist upon the way the general public views pain relieving medications.

Many reports of the harm allegedly caused by analgesics are, in fact, due to misuse of the products by the drug dealers and the drug abusers they were never intended to reach. **But the greatest travesty is that such reports miss the point that these abusers are stealing critically needed pain care from all those who need their powerful effects to make life livable.**

The effectiveness of pain relievers is turned inside-out when criminal abuse is given more attention than the still-unmet need for full and aggressive relief of legitimate patients' chronic pain or cancer pain. That's why it is so important that the media and public officials be made aware of the real issues:

- **Criminals and drug abusers are threatening to complicate or prevent legitimate access to the very medications that chronic pain sufferers need most.**

- **These patients with chronic pain can no longer “suffer silently” and may be denied the medications and adequate dosing they require. They will vociferously make their case known by “suffering out loud.”**
- **We cannot allow drug abusers to dictate our public health policy.**

These three messages reduce the issue to a few words – exactly the terse format that reporters and public officials like to utilize to express themselves on important matters. The words in these message statements should become your mantra in every contact you make with people in a position to tell the story of what’s really going on in the field of chronic pain management.

Why the Greatest Media Impact Comes from Professionals and Consumers Speaking Out ...not the Pharmaceutical Industry

Despite the pharmaceutical industry's resources, it is not the most effective voice in issues of treatment needs. That is because the industry has a recognized and appropriate business self-interest in promoting the use of its products and, as a result is viewed by the media as potentially biased when commenting on the need for its products. Furthermore, the majority of reporters have limited personal experience with healthcare or chronic illness. What's more their sympathies would lie with those parties who have no financial interest in seeing a medication used more widely and more frequently – not with major pharmaceutical companies. It is thus your voice and the voices of your colleagues that the media really want to hear and will find the most credible.

Patients who can tell their own story (before and after treatment), interviews with doctors who can tell how much better patients have done since the new treatment protocols began to promote more appropriate pain control, and word portraits of patient groups indignant that prescription pad thieves and other criminals are stealing access to much needed medications for pain—all have high interest and credibility with the media. In these situations the patients and their advocates are speaking for themselves.

Talking Points

Talking Points are media jargon for the pithy, condensed list of facts or positions on pain issues that that you'll want to convey in a letter, an editorial, a speech or an interview.

More than an outline, talking points are facts to be repeated over and over to be sure they get across. When you deliver talking points verbally “on your feet” you usually have only a very short time to speak and what you say is sure to be edited down to brief “sound bites”, so you need to help out the interviewer by preparing and using the sound bites you want him/her to pick up.

When being interviewed by a reporter for newspaper or TV/Radio materials, don't let yourself be diverted from your talking points by entering into discussions of side issues, always quickly come back to the re-statement of your talking points and point out that they are the reason you are doing the interview.

Later, when we fully discuss how to help a reporter do a great interview, we'll reemphasize another key point: *Be certain to answer the important question—whether it has been asked or not*. Even though you've told a reporter exactly what you'd like to speak out about, he/she may ask a series of questions that don't quickly get to your topic, *so you must answer BOTH the question at hand AND the question you want to answer in order to get to your key talking points*. Just transition into the information that you set out

to deliver while you address the question that has been put to you. If you practice this with friends, you'll find that it is easy to be sure you get your points in, no matter where the interview tends to roam.

Talking Point 1: Effective pain relief is being stolen ... from the patients who need it. Now that adequate therapies have given patients suffering from chronic pain their lives back, concerns about a small number of drug abusers threaten to block access to these treatments

Talking Point 2: Patients with severe pain won't 'suffer silently' anymore...we're suffering 'out loud' because public officials and the media need to hear how we're being threatened with the potential loss of pain medications we require to get on with our lives. Reactions of the media and public officials to the criminal acts of prescription thieves and chronic drug abusers are placing barriers to our access to the medications and regimens that finally work.

Talking Point 3: Chronic pain sufferers can't allow drug abusers and diverters to set our public health policy and deny us treatment ...The criminal acts of drug pushers and abusers are not justification for restricting the availability of the effective pain treatments we've sorely needed to overcome the under-treatment our country's pain sufferers have endured too long. Our treatment needs should come first.

How to Get Your Message Out

There are many ways to communicate your concerns to public officials and the media. Some of the following tools will “fit” best with the way you and your organization wish to be heard. The key here is that the media and gatekeepers to therapy all need to hear your message, and that the greater the variety of ways they receive these messages, the greater their perception of the depth and breadth of your support. If you are aware of other groups interested in appropriate treatment of chronic pain and cancer pain, you may want to work together using some of these tools or you may each find a different set of tools that works best for you. What is key is that every voice be heard.

Why Consistent Repetition is Key

Repetition, especially from multiple sources, is the key to implanting new ideas and information. All of us are bombarded with thousands of messages every day. Newspapers, magazines, radio, television, billboards and the Internet all are putting us in a state of information overload. To have your message heard clearly above this background noise requires that the officials and media you are targeting be exposed to your talking points regularly and from many different avenues. That is why letters, postcards, press releases, interviews, and meetings with sympathetic organizations will be needed to weave TOGETHER the sense of urgency and importance that will focus the minds of your key audiences onto your Talking Points. However, the “background noise” of competing messages will not disappear, so you need to keep the repetition going until you achieve your results.

The following pages provide simple, concrete examples of tools that will work for you in keeping this repetition of messaging alive. You’ll be able to use these tools immediately, without any prior experience.

These sample documents are provided as illustrations only. You must tailor these materials to fit your own experience and the facts as you know them.

Rules for Talking With Reporters

Reporters, as a group, adhere to certain ideals, most notably the principles of objectivity, impartiality, comprehensiveness, independence, and timeliness. As individuals, many reporters would cite an altruistic motivation, i.e., a belief that journalism is a noble pursuit, that it provides a service to society, and that they would hope, by their practice of the craft, to contribute to the improvement of the human condition.

As is true of all human endeavors, reality often falls short of idealism. What's more, journalists are compromised by increasing pressures to remain competitive within their industry. This generally means making sure to have covered stories appearing in competing venues, and—in large part—basing editorial decisions on perceived public interest. In the interest of “being first” reporters are apt to draw rapid conclusions, even about complex topics. Arriving at coverage decisions, deciding which angles of a topic to emphasize, and promoting the resulting product (via headlines, or on-air “tease” announcements) clearly represents a subjective process. It is safe to say the greater the emphasis on any or all of these issues, the greater the compromise of the basic tenets of journalism listed above. Indeed, most claims of irresponsible distorted, or sensational reporting can be attributed to efforts to “push the envelope” in the interest of attracting reader or viewer attention or “scooping” the competition.

Inasmuch as drug abuse consistently ranks among American society's greatest concerns, the news media is well primed to engage the subject,

especially when a “new angle” appears. It is, therefore, not surprising that reporters have taken quick notice of the “drug diversion” phenomenon. In light of the threats to journalistic integrity discussed here it is also not surprising that coverage of this issue has often been incomplete and, therefore skewed against the legitimate interests of those who rely on these pain relievers in their appropriate indications.

It is our challenge, therefore, to expand the horizon by cooperating with reporters as we confidently and thoroughly present those issues presently overshadowed by dramatic stories of product mis-use and abuse.

Our job is primarily one of bridging the gap in reporter understanding and awareness. The challenge, though great, is diminished to the extent we can appreciate the reporters’ perspective and endeavor to expand on that view. Doing so, we can begin to embrace the news media as partners rather than adversaries.

First, it is important to acknowledge that reporting about the potential for abuse of pain relieving drugs is legitimate and newsworthy. We cannot and should not attempt to squelch attention paid to that issue. What we can do is encourage reporters to go beyond the abuse story and develop those issues that are important to pain patients. It is important for them to see that isolated criminal behavior “by a few” threatens thousands of patients’ access to the optimal treatment they have only recently gained.

Reporters must become familiar with the value of these medications for legitimate indications, e.g., the management of cancer pain or chronic back

pain. On a national and regional level, we can help build the case by reviewing the medical literature for the most compelling studies in support of these medications. Principal Investigators of these studies might be approached as sources for the balanced coverage you need.

We should also solicit the support of local chapters of cancer organizations who can offer clinical (patient) and family-member examples of how more appropriate medication improves quality of life for people with cancer. An essential aspect of this discussion should revolve around a person with cancer's inviolable right to effective pain management, and also the right of patient family members to be comforted by the knowledge that their loved one is being fully and effectively managed for pain. Exposing reporters to this side of the story presents them a new, compelling angle that satisfies their basic need for balanced coverage (remember the ideal) as well as their practical need to create compelling journalistic products through the inclusion of drama, urgency, and high emotion.

The most effective press releases along this line will come through partnerships. To the extent that others can be cited to advance our argument we are served in several important ways: first, the message becomes more easily disseminated via multiple voices; second, the message gains credibility in the media's eye because advocates do not have an economic motive for the continued availability of pain products. (This credibility is necessary to counter the media's initial bias that the movement for appropriate pain medication may be more mercenary than humanitarian.) Support from patient groups, caregivers, and medical professionals as well

as support from other advocacy communities will greatly assist in that process.

Now for some specifics insights about dealing with reporters:

1. Assume everything that is said (or shared in written form) is “on the record” and will be published -- unless the reporter specifically agrees to receive “off the record” information IN ADVANCE (before it is shared). The safest posture is to assume that any information shared with a reporter can be expected to be made public.
2. Do not ask to approve copy or script before it is published. It is however, appropriate to offer to clarify issues and to encourage reporters to “get in touch,” to “double check” quotes or to otherwise resolve any potential confusion.
3. Do not allow yourself to be maneuvered into making statements with which you do not agree. Answer honest questions, honestly, but do not answer “loaded” or ignorant questions. It is appropriate, when confronted with such a question to calmly and politely explain why the question is erroneous or misinformed.
4. Do not repeat negative remarks in your answers to questions. If a misinformed reporter asks “Isn’t addiction to pain killers the issue here?” You should not begin your

response with “addiction to pain killers” but, rather say something like “No, the real issue is whether appropriate therapy for thousands of pain patients is being threatened by criminals and chronic abusers.” In this way you state your position in your own language, and *do not repeat* the bias hidden in the reporter’s question.

5. Do emphasize the points you consider most important. In fact, say so. “This is an important point.” “This is what people really should remember.” “Let me explain this key point.”
6. Avoid being argumentative. Be patient but firm regarding inappropriate lines of inquiry, (Number 3 above)
7. Offer feedback after publication: Praise good work, offer constructive criticism for unbalanced reporting. If the report is blatantly unfair (in light of key information provided but ignored) consider an office conference with the reporter and editor to go over the key points again. If the conference is low-key and convincing, further coverage may be arranged.¹
8. Read the publications. Watch the television stations. Become familiar with columnists and editorial writers. These “opinion leaders” can be courted as invaluable assets for getting the right word out.

9. Link the story to related, pertinent issues. For example, there is tremendous public and press interest in *end-of-life issues*. Your position gains instant support by referencing the interest of professional and lay people alike in providing for compassionate and effective palliative care. Pain control is one of the most important elements of this care and is an essential component in the argument against euthanasia of physician-assisted suicide.

Overtures to radio talk shows can be initiated as part of any of the techniques we've discussed. Your approach might be tied to some "breaking news" about the misuse of effective pain medications. While that approach might appear to be counterproductive, it is important to consider for two reasons. First, it instantly answers the reporter's objective of featuring a "timely" or "top-of-the-news" topic. And secondly, taking stock of the negative news (as a springboard to discussing the important points we want to make) demonstrates a steady hand, a confident approach that acknowledges the "abuse problem" while passionately defending the rights of patients to have access to powerful and important advances in the control of human suffering.

¹ This strategy could be employed in initiating new coverage by citing prior coverage. "We have followed your interest in this story in the past and would like to meet with you to discuss new and important developments (or angles)."

Notes on Working with Television Stations:

- Television, by definition, is a particularly “visual” medium and seeks out pictures that display emotion or activity. The weather isn’t usually big news, but its always covered, because someone standing in a storm is so graphic. Next in interest to TV producers is healthcare news. That’s why an emotional statement about suffering and the pain relief provided by more appropriate treatment would be highly attractive footage for local stations.
- When planning to interview on camera, avoid striped, patterned or plaid garments since they glow when broadcast, stealing attention from your comments. Similarly men should wear plain ties with preferably blue shirts (white glows disturbingly, too) and a dark solid colored suit or blazer.
- When thinking about your answers, don’t look up or to the side, it comes across as devious, look right at the camera just the way you would look a friend in the eye when talking.
- Always look into the lens of the camera with the red “on light” glowing, rather than directly at the interviewer. This looks more natural because TV viewers see the interview from the point of view of the camera lens, not the interviewer’s eyes.
- Rather than “wing-it”, sit down with some colleagues and let them fire a few questions at you (including some doting on drug abusers as

victims) so you won't be put in the position of formulating answers for the first time while you are on camera.

- Relax. An honest cause and a thoughtful person are easily conveyed by the camera.

Samples of Tactical Tools and Guidelines for Their Effective Use

Please Note:

These sample documents are provided as illustrations only. You must tailor these materials to fit your own experience and the facts as you know them.

How Write-in Campaigns Help

Write-ins are perhaps the easiest way to reflect a groundswell of support for an important action or idea. Essentially a write-in campaign is an informal poll or vote expressing (in *numbers* of committed individuals) a strong constituency in support of public action. While petitions are one way of doing this job, they are a time consuming way to collect signatures of supporters. The best way is with pre-printed post cards or letters that individuals can sign and mail to your key audiences.

Note: If you include an envelope and/or stamp with the letter or card, you vastly raise the probability that the card will be mailed. You can also issue cards at civic, professional or patient group meetings and collect them to be stamped later as a group.

Another way to do write-ins is to circulate a flyer with the sample message (and list of intended recipients) and, in the flyer, ask people to write their own cards and letters. This is a far less reliable method, because it doesn't eliminate all the intermediate steps (from writing to stamping) the way prepared cards and letters do.

Please refer to the sample postcards and letter on the following pages. (These sample documents are provided as illustrations only. You must tailor these materials to fit your own experience and the facts as you know them.)

Sample Postcards for Write-ins

We Won't "Suffer Silently" Any Longer

Dear Attorney General _(name)_____

I am writing to express my concern that any action to restrict the availability of effective pain medications will seriously jeopardize my treatment for pain associated with _____(illness/condition)_____. For too long we have been under-medicated for our pain and we finally have appropriate medications and regimens that fully treat our conditions and permit normal daily living activities. Please do not let the need to curb a small number of drug abusers keep us from receiving the medications we need.

(signature)_____ (date)_____

(print name)_____

(address)_____

We Won't "Suffer Silently" Any Longer

Dear County Sheriff_(name)_____

Something very important is being stolen in our county -- our access to the appropriate medications that we sorely need to effectively treat our severe pain.

(Circle one) I --- My close family member ---- My good friend --suffer(s) from pain caused by -(disease/condition))_____ and has finally been getting the appropriate treatment that had been denied for years. Now we hear that in order to prevent a few criminals and chronic abusers from stealing these medicines, we may have restrictions on them or limited access to them. Please do not let the majority suffer for the sake of a few criminals. Please make these effective medications fully accessible to patients in need.

(signature)_____ (date)_____

(print name)_____

(address)_____

Sample Letter for Write-ins

Your Name & Address

Name of State Attorney General or County Sheriff
Address

Dear _____

We Won't "Suffer Silently" Any Longer.

I am writing to express my concern that any action to restrict the availability of appropriate pain medications will seriously jeopardize my treatment for severe pain associated with _____ (illness) _____. For too long we have been under-medicated for our pain and we finally have effective medications and regimens that fully treat our conditions and permit normal daily living activities. Please do not let the need to curb a small number of thieves and drug abusers keep us from easily accessing the medicines we need.

_____ (signature) _____ (date) _____

_____ (print name) _____

_____ (address) _____

The Key Audiences for Your Message

The audiences you'll want to focus upon are:

- Your state Attorney General and Governor
- County Sheriff and/or Local or State Police Chief
- Your State Health Commissioner
- US and state Representatives and Senators are also important—especially if the legislator has a family member being treated for chronic pain.
- See pages 33-34 for examples of additional potential audiences

The “Op-Ed” : A Special Opportunity To Speak Out In Your Local Newspaper “Guest Editorial” Column

Most newspapers openly invite representatives of important local civic and professional groups to speak their minds by submitting special “guest editorials”. Such “op-ed” essays (since they’re printed opposite the editorial page), are often titled “My Turn” or “My View,” and are a great platform for stating the reasons for your personal (or group) advocacy of appropriate treatment for pain.

In cases where negative coverage appears in local newspapers, these guest essays provide an accessible and vital tool to “balance” any news coverage that doesn’t acknowledge your cause. Just call the newspaper editorial page editor to offer an article. (You might tell them you are available for comment as part of their news coverage of the issue as well).

How to Enlist Civic Groups Who are Interested in Your Cause

You are probably aware of a number of local and national civic groups that are not healthcare oriented on the surface, but in fact do support healthcare issues and patients' rights issues as part of their agenda. Usually these groups represent constituencies that coincidentally have an inordinately high incidence of a given disease. For instance, the National Business & Professional Women's Association and its local state chapters are actively involved in breast and uterine cancer treatment issues because their membership is entirely women; AARP works in diseases of mature adults (including depression, and cancer which inordinately affect Americans over 50); and the National Governors' Spouses Association annually chooses three or four major public health areas for local programs to be implemented by each state.

These groups represent huge memberships and powerful constituencies that can throw their added weight behind your efforts if they see that a significant part of their membership shares the medical need you are exposing.

Using the chronic pain associated with terminal breast cancer as an example, it would be logical to gain the allied support of your local chapter of the National Association of Business and Professional Women and enlist them in your write-in campaign and as co-advocates in group interviews for the

local newspaper or radio / TV station talk shows, as well as medical segments on the local morning or evening news shows.

The best way to approach these relationships is through the individuals in your group who are also members of the civic group you are approaching. Whether or not you have a member in common, a simple lunch or dinner meeting usually lays the groundwork for a wonderful alliance. Next steps would be for the groups to invite each other's President to speak on shared interests and then form a joint committee to put together a plan to use this toolkit for your cause.

Here is a brief sample list of organizations that may be interested in joining your efforts.

- Clergy associations dealing with pain, terminal illness
- Hospice associations
- State or regional medical society (oncology, rheumatology, trauma and orthopedic sub-groups)
- Local Senior Citizens' groups
- Muscular Dystrophy, Paralysis, Spinal Injury groups
- Local/ State Chapters of:
 - National Association of Business and Professional Women
 - Delta Sigma Theta (national African American college graduates sorority)
 - National Governors' Spouses Association (State Chapters)
 - Women's Cancer Awareness groups

- Groups such as Masons, Odd Fellows, Elks, American Legion, VFW, Grange, Vietnam veterans groups
- The Arthritis Foundation
- American Cancer Society
- American Society for AIDS Research; AIDS patient groups
- Knights of Columbus
- Nursing Associations
- Cancer Survivors' Groups (usually reached through hospital)

Distributing Informational Flyers

A good way to educate (and ultimately enlist) people to your cause is the informational one or two-sided flyer. One-sided flyers are easy to desktop publish and run off at copying centers at minimal cost. The most effective flyers make only a few key points concisely and refer readers to phone numbers for more information. Too much cluttered information simply won't be read.

Colored paper is an attention getter and a catchy headline helps too. We recommend "We're Not Going to Suffer Silently Any More" because it states your mission to raise awareness of the need for access to appropriate treatment and to the effective medications that kind of treatment requires.

Some excellent distribution points are:

- Outpatient rehabilitation centers
- Waiting rooms of physicians and physical therapists sympathetic to your cause
- Nursing Home waiting / reception areas
- Counters of Pharmacies sympathetic to your cause
- Health fair booths
- Local hospital Pain Education courses
- At meetings of your groups and their civic group allies
- As mailings to members of concerned families of identified pain sufferers in your groups

If the flyer is organized as a “Fact Sheet” (see Press Kit discussion), then it can also be included in mailings to public officials and reporters who’ll seize upon the statistics.

Please turn to the next page for sample one-sided flyer.

(These sample documents are provided as illustrations only. You must tailor these materials to fit your own experience and the facts as you know them.)

The survey statistics cited in the following document are drawn from two reference sources:

1. Survey of Pain In America: 1999, conducted by NFO Research, Inc.;
2. NIH Guide: New Directions in Pain Research I., Washington, DC: GPO, 1998

We're Not Going to "Suffer Silently" Any Longer

After a long struggle to stop the under-treatment of chronic pain sufferers, a new threat has surfaced challenging our ability to finally lead more normal lives. Just as the guidelines have been revised to permit more appropriate treatment of pain and as more effective pain medications have become available, criminals in some rural areas are jeopardizing these advances. These unscrupulous drug diverters and abusers steal physicians' prescription pads and deal in prescription drugs for monetary benefit, but they've done even more damage to those of us who suffer from chronic pain and cancer pain. The criminal acts of a few have put momentum behind a movement to restrict access to the very medications that have recently changed our lives for the better.

If you or a family member or friend is being treated for chronic pain of cancer, or other debilitating disease, please join us in writing to state Attorney General _____ name _____ and to your County Sheriff and legislators to insist that our successful new treatments not be jeopardized by the criminal few who are profiting from drug abuse.

If you want to make your voice heard, use the attached to register your support of full access to medication for chronic pain sufferers. In the column at the right are some important pain facts that you should know about. For additional information please call or write: _____

PAIN FACTS:

- Some 50 million Americans suffer from pain
- Until recently, most chronic pain has been under-treated
- Physicians now concur that suffering can be reduced and lives mended by new pain management treatments, including opioid analgesics.
- In nearly half of America's households at least one member suffers from chronic pain.
- For one-third of sufferers in a recent survey, chronic pain was so severe and debilitating they felt that they could not function normally.
- Back and joint pain, arthritis, headaches, nerve problems, surgical pain and injuries are the most common causes of severe chronic pain.
- 56% of patients surveyed say pain interfered with sleep.

Speaking at Civic Organizations

While the printed word and interviews are excellent communications tools, nothing is more moving than the voice of a committed speaker. Take advantage of the opportunity to speak to groups that can be allies in support of the cause you know so well. Use the opportunity to briefly speak as intellectual leverage for your cause by arming the audience with facts that strongly make the human case for full access to appropriate treatment for chronic pain.

Whenever possible supply fact sheets or handouts with write-in cards so the audience can act right away in demonstrating their support--while you've got them motivated. Also offer to speak to other groups to which the current audience may also belong.

While we've provided a sample 5-minute talk in the next few pages, keep in mind that it is a sort of outline of key points in your story. You will need to modify the language and make it your own so that it reflects your viewpoint and you can speak naturally and you let your personal convictions show through.

Talks to civic groups or professional groups also are great opportunities to invite the local press. You'll want to study your newspaper to identify the reporters who cover your town or health topics. They'll listen to the talk and ask good questions that will extend the impact of your remarks into an article in the local news. When inviting reporters, be sure not to overlook the local *weekly* newspapers, they are often hungry for unique "human interest" news stories.

A sample 5-minute talk is provided on the following pages.

(These sample documents are provided as illustrations only. You must tailor these materials to fit your own experience and the facts as you know them.)

Sample 5-Minute Talk

I would like to thank _____ (Program Chair's name) _____ and the _____ group's name _____ for inviting me here to speak with you about a subject that is very important to me personally. It's about medical progress that is at risk of being stolen and held hostage -- and it's about criminals getting more consideration than the suffering, chronically ill patients they've robbed.

If anyone in this room has ever suffered serious back pain, you know how debilitating the pain can be. Once pain strikes, you hesitate to make the slightest move. Now imagine back, joint, arthritis or trauma or cancer pain even more severe and life-hindering than that back pain---and you've entered a new league. That is the league that severe chronic pain sufferers are in. And strangely enough—even though effective medications have been available—physicians had been underutilizing them.

In the last couple of years, this travesty has been overcome. Extensive chronic pain research has revealed that appropriate use of effective medications can not only dramatically ease patients' suffering but help return them to much more normal lives. Unfortunately however, just as physicians have embraced this new approach and patients have begun to receive effective new medications, drug abusers threaten to limit -- and perhaps even end-- this new era in pain therapy.

Drug pushers and chronic abusers in rural America have little access to the illegal drugs that are available in large cities, so they steal prescription pads,

fake illnesses, and even forge prescriptions to get their hands on the medications designed to help pain sufferers. To combat this problem, public officials unfortunately are considering a move that would undo the very advances that we've made in pain therapy by restricting access and perhaps even eliminating the use of these products.

The popularity of this simplistic solution is such a threat to pain sufferers that they have been organizing themselves and have vowed to "suffer silently" no longer. From now on, patients with chronic pain are determined to "suffer out loud" to call attention to their needs and the fact that the many who suffer should not be robbed of effective medical treatment by criminal drug dealers and abusers. Their caregivers and their healthcare professionals are also organizing an effort to support this movement, and that is why I am here speaking with you today.

I'd like to briefly site a few facts for you and then ask for your support in moving our public officials to act to prevent tragedy from striking pain sufferers, especially those with serious injuries or cancer pain.

Fact 1: In a recently conducted survey of chronic pain patients it was determined that almost half (43%) of America's households has a least one member who suffers from chronic pain due to a specific illness or medical condition.

Fact 2: One third of sufferers in the same survey have pain so severe and debilitating that they feel they can't function as normal people; they say sometimes it is so bad they want to die.

Fact 3: More than half of those surveyed said they've suffered from chronic pain for over five years.

Fact 4: One third of the sufferers surveyed –and this is the most disconcerting finding—do not believe people understand how much pain they are in, and one quarter say their family is tired of hearing about their pain and doesn't understand how it affects them. That same 25% feel inadequate as a spouse or partner because of the pain.

This sad state of affairs can change with appropriate treatment regimens using the effective medications now available—but that won't happen if the latest advances in pain relief are hijacked by prescription thieves, drug dealers, drug abusers and other criminals.

Thus I ask that if you are as alarmed as I am, you will take some of the post cards we've distributed and use them to let your public officials know that we want patients to have appropriate access to the medications and treatments they need. I've also put out some chronic pain fact sheets, for those of you who would like more information; and in closing, I'd like to say that I'd be happy to take this message to any other group you would recommend to me.

Thank you for listening.

The survey statistics cited in this document are drawn from two reference sources:

1. Survey of Pain In America: 1999, conducted by NFO Research, Inc.;
2. NIH Guide: New Directions in Pain Research I., Washington, DC: GPO, 1998

Sharing the Stage with Committed Public Officials

Another great way to get out the word on chronic pain and cancer pain needs (and to even neutralize less than sympathetic individuals) is to participate in a roundtable discussion at a medical group, hospital forum or civic organization meeting.

Sharing the stage helps the public to see that people from a variety of walks of life and professions all want to see appropriate pain therapy made available.

Often the meeting can be led by a moderator who helps the group to reach a consensus statement to be published in the newspaper or in a medical publication. Since these meetings are a gathering of several community leaders you can often get press coverage when you announce the meeting topic and participants—then again while the meeting is being conducted – and a third time when the proceedings and consensus statements from the meeting are released .

Detractors should not be excluded from these discussions. Listening to the majority of their respected peers take a different view from their own often motivates detractors to take a more moderate position and, in effect, acknowledge that although they do not entirely agree---there is merit to your view that patients are, indeed, at risk of being denied appropriate treatment.

Additional Tips

1. Your open forum program will gain added credibility and publicity if held under the aegis of a prestigious civic club that is known for presenting public issues. Every major city has such an organization, and someone in your group probably has an acquaintance there who is worth contacting.
2. When you attend a forum, you need to be prepared with the fact sheets included in the press kit (see press kit section) and you need to stay on message. That means you should keep getting back to your two or three talking points whenever possible.
3. It is important to be fair and acknowledge those who are sympathetic to chronic drug abusers—certainly abusers are in a hopeless spiral and need treatment, too. However the plight of abusers does not justify criminal behavior or stealing the opportunity for chronic pain sufferers to be appropriately treated and, as a result, lead more normal lives.

Using a Press Kit

Releases, Questions & Answers, and Fact Sheets / Backgrounders

Your “Press Kit” is a folder that contains simple, highly useful summaries of information that describes and documents the story of recent innovations in chronic pain treatment and explains how this treatment advance is being threatened by criminals and drug abusers.

The kit contains three major types of documents:

1. A Press Release that states your case in the format of a pre-written news story (see following sample)
2. A Q&A document that poses the most anticipated questions about the issue and then answers them (see sample)
3. A Fact Sheet or two that use simple bulleted points to list supporting background information or statistics. (Sometimes a three to four page document called a “backgrounder” serves as an even more elaborate reference document). (A sample fact sheet is the flyer shown earlier.)

Whenever speaking with the media or giving a talk, distribution of these “take away” materials helps to fill in the details that help build your case for the appropriate treatment of cancer pain and other chronic severe pain.

Sample press releases and Q&A documents are on the following pages.

(These sample documents are provided as illustrations only. You must tailor these materials to fit your own experience and the facts as you know them.)

Sample Press Release #1

For Immediate Release

Contact: name, phone, e-mail

“Suffering Out Loud” To Get Treatment They Need: Chronic Pain Patients Are Worried About Medication Restrictions

(Your city / Date) Ms/Mr.. (name) says she/he can no longer “suffer silently” from severe pain but is stating “out loud” that the behavior of criminals and drug dealers is threatening the availability of the effective treatment that has been making her life livable again.

“Thousands of others share the same fate, “ said Ms/Mr (name) a retired teacher in the (city) school system and vocal advocate for pain sufferers, “a few drug dealers and prescription thieves in rural areas are prompting public officials to consider restricting the availability of the advanced treatments we’ve needed.”

Until recently doctors had been taught to withhold advanced pain-killing medications from people with cancer, arthritis or back pain, but new studies show that this practice constitutes serious under-treatment of such conditions. New guidelines call for more appropriate use of analgesics, but just as physicians have seen success with their patients,

////more////

official reaction to drug abusers and prescription thieves in rural communities threatens to restrict access to these medications by the thousands of patients who would benefit.

“We’re asking public officials to deal sternly with the small group of criminals who are hijacking and abusing the medications we need,” stated Ms/Mr., “under-medication was a serious problem for those of us who wanted to resume a normal life-style, and now that more effective medications are finally doing the job, we want our public officials to assure us that treatment will remain readily available.”

Over 10 million patients were treated for chronic pain last year and a recent survey indicates that nearly half of American households (43%) include at least one chronic pain sufferer.

Ms (name) and other members of the (name) organization are calling for fellow pain sufferers and their caregivers and families to write to the (state name) Attorney General demanding open, unrestricted access to these necessary pain medications.

For more information the organization can be reached at (phone/web).

///end///

Sample Press Release #2

For Immediate Release

Contact: name, phone, e-mail

Local MDs Concerned About Risk to Chronic Pain Patients Worried that Medication Restrictions Will Prevent Proper Treatment

(town/date) *Town name* physicians are calling on state Attorney General (name) and County Sheriff (name) this week to underscore the need for unrestricted access to advanced, more appropriate pain treatments in their battle to prevent under-treatment of local patients suffering from severe chronic pain.

Whether back pain, cancer pain or pain from serious injuries, new study data have shown that stronger treatments work better to relieve suffering and return patients to more normal lives. However, the rising incidence of abuse among chronic drug abusers now threatens the availability of this new treatment regimen because public officials are considering restricting availability of the most effective medications.

Calling such restrictions a “step backward in treatment of pain” (name of local MD) is leading a delegation of patients, caregivers and concerned healthcare providers to visit the Sheriff and Attorney General to help retain full access to medications for patients in (our town).

///more///

“Patients with severe chronic pain tell me they are tired of suffering silently. After years of under-treatment, physicians are now being taught to fully utilize the medications available –but just when we are seeing dramatic results in our patients—a few criminal abusers and drug dealers are posing a threat to this life-freeing new treatment regimen.”

Rallying around the cry that they’re going to “suffer –not silently—but out-loud” until open access is assured, these patients cite a recent survey of pain sufferers revealing that:

- Nearly half of America’s 44 million households (43%) includes at least one chronic pain sufferer
- One third of suffers have chronic pain so severe they can’t function as normal people---some, at times, even want to die
- One third of sufferers do not believe that people understand how much pain they are in, and one quarter say that their family is tired of hearing about the pain—doesn’t understand how it affects them –and this makes them feel inadequate as a spouse or partner.

Dr. (name) commented that its the life-impeding effects of chronic pain that the new, more effective treatments are finally putting to an end. He said he was calling on public officials to make sure that no patient is denied optimal treatment due to the illegal acts of drug dealers and abusers.

Dr (name) is part of the local (group name) group and encourages interested readers to contact them at (phone) for more information. ///end///

Sample

‘Questions & Answers’ About Chronic Pain Treatment

1. **Q.** How many Americans suffer from chronic severe pain.
A. Based on a recent survey, at least one member of nearly half (43%) of America’s 44 million households suffers from chronic pain due to a specific illness or medical condition.
2. **Q.** How effective has treatment been?
A. Patients in chronic pain have been so dissatisfied with the efficacy of their prescription medications and over the counter medications, that 78% were willing to try new treatments, and 43% would spend all their money on treatment if they knew it would work.
3. **Q.** How is treatment improving?
A. New study data have moved physicians from a past history of under-treatment of pain to the active use of more appropriate medications and a more appropriate treatment regimen. This change in the attack on pain is giving more normal lives back to chronic pain sufferers.
4. **Q.** Just how much does pain affect patients’ activities of daily living?
A. 56% of chronic pain sufferers complain that pain interferes with sleep. They also say it affects their overall mood (51%), ability

to drive (30%), have sexual relations (28%), and perform simple daily tasks like feeding themselves (7%).

5. **Q.** How long on average do patients have to cope with chronic pain before receiving real relief?

A. More than half of patients surveyed have been suffering for at least five years. Even for those patients who say pain is under control, it has taken a long time for appropriate treatment to be found.

6. **Q.** Now that more appropriate treatment is recommended, shouldn't this situation improve?

A. Yes, but a growing threat to the success of the new treatment is the criminal behavior of a small number of drug dealers and prescription thieves who divert the medications to abusers. In the attempt to limit this criminal behavior, some have proposed restrictions to medication access that would seriously hinder treatment for thousands of chronic pain sufferers.

7. **Q.** What is being done to prevent "stepping backward" from modern pain management ?

A. Patients, healthcare professionals and care givers are organizing to stop "suffering silently" and make the voice of their suffering heard "out-loud" so that public officials do not permit a few criminals to steal this advance in treatment from the thousands of patients in need. Restricted access to appropriate medications

is unacceptable to pain sufferers who are finally getting their lives back to a semblance of normality.

8. **Q.** What can be done to control criminal diversion and abuse?

A. Tamper resistant prescription pads are available, and community education programs are being conducted by some companies to help curb abuse. Also, as medications are being developed, formulations to discourage abuse are being tested. But, for now, we cannot sacrifice appropriate treatment of the millions of responsible chronic pain sufferers to the criminal activity of a few abusers.

The survey statistics cited in this document are drawn from two reference sources:

1. Survey of Pain In America: 1999, conducted by NFO Research, Inc.;
2. NIH Guide: New Directions in Pain Research I., Washington, DC: GPO, 1998

Identifying Yourself as Part Of A Nationwide Movement

One of the ways we all measure the importance of an idea is by evaluating whether support for the idea is embodied in a growing regional or national trend. It is human nature to pay attention to news of a groundswell of support for action, and the origin of such trends is often referred to as a “grassroots” movement---that is, a phenomenon that arose from people’s basic concerns.

As a movement grows and is acknowledged, the media and public officials pay greater attention. Here are some ways to establish visibility for your local grassroots groups and link them to a trend that public officials and the media must acknowledge and deal with:

1. Name the group in an attention-getting manner that describes your mission.
2. Use the group name on all literature, letterheads, and correspondence via e-mail and as an affiliation when seeking press coverage or appointments with public officials. Government officials and the media are far more likely to give time to the President of the Boston Chapter of The Pain Relief Coalition, than to an MD or patient on their own.

3. Be sure to cite how many members (or member organizations) you represent locally, regionally and nationally. And don't forget to provide statistics about the millions of patients who deal with cancer pain and chronic pain daily. The media loves statistics and public officials often equate an issue's importance to the size of its constituencies.
4. You may want to suggest to a reporter or editor that there is national interest in the issues of your local story—that means that they may get their local article picked up and reprinted by the national news desk of their newspaper chain. The same applies to local TV and radio. In, fact you may want to call in to local stations and request an interview presenting the local view of a national story on pain and pain treatment that they have already aired.

How to Alert Purdue Pharma's Public Affairs Professionals About Promising News Opportunities

Committed advocates for protecting the rights of people in pain share a noble objective. Your vigilance, perseverance, and energy to carry out this work are fueled by an appropriate sense of urgency rooted in a morally correct position.

A coalition representing diverse disciplines but joined by this common interest could be established in every community threatened by misuse and abuse of analgesics; and your participation in a broadly based advocacy network also allows you to monitor local news and events. Signs of challenges to “patient access to appropriate pain treatment ” gleaned from different local perspectives can be effectively countered by forming state, regional (and perhaps national) coalitions. By this mechanism novel and powerful retorts can be crafted to neutralize unfair or unbalanced news coverage.

Your approach might include outreach to the law enforcement community, as well as representatives of communities most at risk for drug misuse and abuse. For within those communities there are large numbers of people who, through personal experience or present circumstances, require the quality pain control available through the legitimate prescription of appropriate analgesics.

In the absence of instances of product abuse, news leads on patient rights, pain control (general), cancer pain, end-of-life care or research in arthritis, back pain, diabetic pain, etc., present opportunities for discussions, articles, or broadcast interviews that tell your story, as well. This news coverage might be based on the general issues surrounding the threats to effective medication posed by the few who abuse these compounds.

Local TV, radio and newspaper coverage provides snapshots of leading concerns within your community. It is, therefore, essential to establish effective monitoring. If you experience periods of active negative or unbalanced reporting, you may want to call them to the attention of Purdue Pharma, should your local group need special assistance.

Partners Against Pain Information Support Resources

Advocacy Contacts: Pamela Bennett,
patientadvocacy@pharma.com

Kevin McIntosh
patientadvocacy@pharma.com

Your Medical Liaison / Account Executive _____

Phone _____ Voicemail _____

Other important numbers:

Local Newspaper _____ Reporter _____

Weekly Newspaper _____ Reporter _____

Local TV Call Letters _____ Reporter _____
Phone _____

Local TV Call Letters _____ Reporter _____
Phone _____

Local Radio Call Letters _____ Reporter _____
Phone _____

Local Radio Call Letters _____ Reporter _____
Phone _____

Use This Page To List Additional Important Contacts